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ABSTRACT

This bibliography covers a wide range of issues related to the needs of adolescents and young adults with chronic illnesses and disabilities and their families. For each item in the bibliography, information provided includes author, title, source, date, and abstract. Price information is given when available. Materials include books, audiotapes, newsletters, comic books, booklets, videotapes, and training packages. The bibliography is divided into "Materials for Youth" (15 items), "Materials for Parents" (24 items), "Materials for Parent Groups" (eight items), and "Other Resources" (which lists six organizational sources and one periodical.) (JDD)

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National Center for Youth with Disabilities

. . . a resource center to improve services for youth with disabilities.

CYDLINE Reviews:

Youth with Disabilities and Chronic Illnesses: An Introductory Guide for Youth and Parents

June, 1990

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A project of the:

Society for Adolescent Medicine
Adolescent Health Program

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The National Center for Youth with Disabilities is a collaborative project of the Society for Adolescent Medicine and the Adolescent Health Program at the University of Minnesota. The Center is supported through a grant from the Bureau of Maternal and Child Health and Resources Development, Division of Services for Children with Special Health Needs, Department of Health and Human Services, #MCJ27361-010. The Center's mission is to raise awareness of the needs of youth with disabilities; foster coordination and collaboration among agencies, professionals, parents, and youth in planning and providing services; and provide technical assistance and consultation.

For additional information on the Society for Adolescent Medicine, contact:

Society for Adolescent Medicine
19401 East 40 Highway
Suite 120
Independence, MO 64055
816/795-TEEN

For additional information on the National Center for Youth with Disabilities, contact:

National Center for Youth with Disabilities
Box 721 UMHC
Harvard Street at East River Road
Minneapolis, MN 55455

1-800-333-6293

or

612/626-2825

National
Center for

Youth with Disabilities

The National Center for Youth with Disabilities (NCYD) is committed to raising awareness of the needs of adolescents and young adults with chronic illnesses and disabilities. In keeping with our mission, we have prepared this bibliography covering a wide range of issues related to youth and their families. This information is intended to provide a brief overview of the issues and selected resources; it is not an exhaustive review. We hope that you will take the time to read through this bibliography and share it with anyone you believe would benefit from the information. The materials listed here with a price indicated can be purchased from the organizations that produce them. Other materials should be available on loan through your public library. Most public libraries have interlibrary loan services through which they can borrow books from other libraries if the materials are not in their own collections.

The information in this bibliography is drawn from the computerized database of the NCYD Resource Library. Contained in the Resource Library is information on journal articles, books, and unpublished documents; training materials such as videos and curricula; and information on model programs that can be used for planning purposes. A Technical Assistance Network of individuals with expertise on diverse youth– and disability–related issues is available to provide technical assistance and consulting. Additionally, the Resource Library offers access to information on federal and state case law and legislation related to youth with disabilities across many service sectors.

You can request specialized searches of the NCYD Resource Library on topics of your choosing simply by calling an NCYD information specialist. This person will then send you the requested information in a format similar to this bibliography. The minimum charge for this service is $5.00. The database is also directly accessible, through menus or a command system, for interested individuals with their own computer and modem. The basic charge for this direct access method is $25.00 per hour with an $11.00 minimum use charge; the user pays any long distance charges. Either way, you can easily receive current information on youth with disabilities that is specific to your particular needs and interests.

Thank you for your interest in the National Center for Youth with Disabilities. If you would like additional information on our Center, or would like to request information about the Resource Library, please call our information specialist toll–free at **1–800–333–6293.**

TABLE OF CONTENTS

Page

I. MATERIALS FOR YOUTH ---------- 1

II. MATERIALS FOR PARENTS ---------- 5

III. MATERIALS FOR PARENT GROUPS---------- 12

IV. OTHER RESOURCES ---------- 15

I. MATERIALS FOR YOUTH

AUTHOR	Rosenberg E;
TITLE	**Growing Up Feeling Good.**
SOURCE	Beaufort Books: NY;
DATE	1983
ABSTRACT	This is a somewhat long but enjoyable guide to the physical and emotional changes of the pubertal years written for those aged 9-14. There are individual chapters on friendship, popularity, dating, peer pressure and decision–making, sexual feelings, competition, substance use, relationship with parents, family feelings and problems, coping with death of a loved one, adapting to disability, school adjustment, and prejudice. (432 pages)

AUTHOR	Chaney S; Fisher P;
TITLE	**The Discovery Book: A Helpful Guide for the World Written by Children with Disabilities.**
SOURCE	United Cerebral Palsy Assoc. of North Bay, Inc: 959 Transport Way, A-1, Petaluma, CA 94952 . 707/765–6770;
DATE	1989
ABSTRACT	An exploration of the psychosocial aspects of physical disability in youth as expressed by 10–15–year–olds with disabilities. Developed by a United Cerebral Palsy support group, the book includes artwork, guided activity sections, and a glossary of terms. Topics explored include: friendship; doctors and hospitals; problems and challenges; goals, wishes, and dreams; and coping strategies. (Available for $7.95 plus $1.00 postage.)

AUTHOR	Drimmer F;
TITLE	**The Elephant Man.**
SOURCE	G.P. Putnam's Sons: New York;
DATE	1985
ABSTRACT	This extremely moving fictional biography of Joseph Merrick, a person with neurofibromatosis, was written for youth and can be recommended to those who wish a better understanding of life with a disability and the human spirit to cope to the best of one's abilities. (143 pages)

AUTHOR	Ducat L; Cohen SS;
TITLE	**Diabetes. A New and Complete Guide for Healthier Living for Parents, Children and Young Adults who Have Insulin–Dependent Diabetes.**
SOURCE	Harper and Row: NY;
DATE	1983
ABSTRACT	Much of the advice and practical suggestions in this self-described primer on coping is from parents, children, and adolescents who have been through the experience, with input from health care professionals. Included are discussions of questions teens ask about diabetes, such as those regarding peer relationships, school, camp, marriage, career, and the management of hypoglycemia. (253 pages)

AUTHOR	Nolan C;
TITLE	**Under the Eye of the Clock: The Life Story of Christopher Nolan.**
SOURCE	St. Martin's Press: New York;
DATE	1987
ABSTRACT	Lyrical autobiography of a 23-year-old man with severe spasticity.

AUTHOR	Miller R;
TITLE	**Robyn's Book.**
SOURCE	Scholastic Inc.: New York;
DATE	1986
ABSTRACT	The journal of a young woman with cystic fibrosis.

TITLE	**Help Yourself: Tips for Teenagers with Cancer.**
SOURCE	Office of Cancer Communications, National Cancer Institute, Building 31, Room 10A24, Bethesda, MD 20892; 1–800–4–CANCER;
DATE	1983
ABSTRACT	This 40–minute free audiotape includes four radio-play style stories entitled "The Day They Told You", "Your Family", "Your Treatment", and "Your Friends". This tape is designed to provide information and support for adolescents with cancer. May be used in conjunction with accompanying booklet.

TITLE	**Candlelighters Childhood Cancer Foundation Youth Newsletter.**
SOURCE	Candlelighters Childhood Cancer Foundation, Suite 1001, 1901 Pennsylvania Ave. N.W., Washington, DC 20006; 202/659-5136;
ABSTRACT	The Candlelighters Youth Newsletter provides information for children and adolescents with cancer, their parents, siblings and professionals on cancer and the young cancer patient. This quarterly publication is an outlet for positive expression for young people living with cancer.

TITLE	**Don't Just Sit in a Big Green Chair!–Living with Juvenile Rheumatoid Arthritis.**
SOURCE	LaRabida Children's Hospial, Rheumatology Program, E. 65th Street at Lake Michigan, Chicago, IL 60649; 312/363-6700;
DATE	1985
ABSTRACT	This 16–page booklet is geared towards the child and how he/she can cope with juvenile rheumatoid arthritis. It includes a brief description of the disease and how to live with it. Areas such as school, sports, social activities and sexuality are addressed in a manner that can easily be understood. (Available for $1.50.)

TITLE	**Space Age Smarts.**
SOURCE	Florida Association of Pediatric Tumor Programs, P.O. Box 13372, University Station, Gainesville, FL 32604; 904/375-6848;
DATE	1985
ABSTRACT	Space Age Smarts is an 8 1/2"x11", 12-page, full color comic book designed for 13–16–year–olds with hemophilia. An alien from the Center of Galactic Health learns about AIDS from a group of teenage earthlings. This cleverly written and imaginatively illustrated comic book encourages common sense precautions to prevent the spread of AIDS. The teens, including one with hemophilia, discuss: transmission, safer sex practices, the dangers of shooting–up, and the importance of people with hemophilia cleaning up their blood spills and disposing of needles. The fact sheet inside the back cover presents more detailed information on what AIDS is, how it is transmitted, the AIDS antibody test, symptoms, and prevention. (Available for $1.95.)

TITLE	**Sexual Abuse: What Is It? An Informational Book for the Hearing Impaired.**
SOURCE	St. Paul Ramsey Medical Center, East Building, 640 Jackson, St. Paul, MN 55101, Attn.: Alice LaBarre; (612) 221-2747.
DATE	1986
ABSTRACT	This text is a 71 page book which clearly explains what sexual abuse is and what to do if it happens to you. It has explicit pictures and minimal language text as well as highlighted vocabulary and a glossary. It can be used for any young person ten years of age or older who needs limited vocabulary materials or for whom English is a second language. (Available for $6.95 plus postage.)

TITLE	**Hearing Impaired Students in Postsecondary Education.**
SOURCE	American Council on Education: HEATH Resource Center, One Dupont Circle, Suite 800, Washington, D.C. 20036-1193; 1-800-544-3284;
DATE	1986
ABSTRACT	This fact sheet is intended for students with hearing impairments and for the professionals working with these students. It provides basic information on: hearing loss itself, communication methods, postsecondary educational options, and types of support services available. Common social concerns are discussed, and advice is extended. Other sources of information and referral, a selected reading list, and a selected resource list are included. Many other materials are also available from HEATH; call for their list of publications.

TITLE	**Publications on Adolescents and Young Adults with Learning Disabilities.**
SOURCE	Association for Children and Adults with Learning Disabilities, ACLD Inc., Literary Depository, 4156 Library Road, Pittsburgh, PA 15234; 412/341-1515;
DATE	1988
ABSTRACT	These publications cover a wide range of issues. Titles include: Legal Rights Primer. Career Planner: A Guide for Students with Disabilities. What About Me: The LD Adolescent Inside Out or Outside In. Learning Disabilities and Juvenile Delinquency. The College Student with a Learning Disability. Preparing for Tomorrow, Young LD's (O)ld. Dispelling the Myths: College Students and Learning Disabilities. Adolescence and LD (A Time Between). A Talking Mouth Speaks About Learning Disabled College Students. School Dysfunction in the Adolescent. The Adolescent with Scholastic Failure. A Shopper's Guide to Colleges Serving the Learning Disabled. Living with a Learning Disability—A Handbook for High School and College Students. JD/LD Where Do We Go From Here? Attention–Deficit Disorder in Teenagers and Young Adults. LD and Delinquent Youth. Clues of LD for the Juvenile Justice System.

AUTHOR Mangrum CI; Strichart SS;
TITLE **Peterson's Guide to Colleges and Programs for Learning Disabled Students (Second Edition).**
SOURCE Peterson's Guides: Princeton, NJ;
DATE 1988

ABSTRACT A comprehensive directory of more than 9000 2– and 4-year colleges and universities which offer special services for students with dyslexia and other learning disabilities. The guide distinguishes between colleges with fully developed programs and those offering some services.

AUTHOR McKee L; Kempton W; Stiggall L;
TITLE **An Easy Guide to Loving Carefully.**
SOURCE Network Publications: Santa Cruz, CA;
DATE 1987

ABSTRACT This guide provides a very clear and uncomplicated presentation of facts about sexuality and reproduction. Simple illustrations on almost every page and extra large type size makes this especially appropriate for people with low–level reading skills or learning disabilities or persons who are developmentally disabled. Subjects include: womens' and mens' reproductive organs, birth control, breast and pelvic examinations, AIDS, chlamydia, and other STDs.

II. MATERIALS FOR PARENTS

AUTHOR Anderson W; Chitwood S; Hayden D;
TITLE **Negotiating the Special Education Maze: A Guide for Parents and Teachers.**
SOURCE Woodbine House: 10400 Connecticut Avenue, #512, Kensington, MD 20895;
DATE 1989

ABSTRACT Negotiating the Special Education Maze provides information on: the Education for All Handicapped Children Act; how to write an Individualized Education Program (IEP); how and where to get information on local school systems' procedures and regulations; easy-to-understand definitions of common terms used in evaluations, meetings and due process appeals; how to organize, prepare, and communicate your observations of a child's problems; and parent and consumer organizations for children and youth with disabilities. (200 pages)

AUTHOR	Bloom B; Seljeskog E;
TITLE	**A Parent's Guide to Spina Bifida.**
SOURCE	University of Minnesota Press, 2037 University Avenue, S.E., Minneapolis, MN 55414; 612/624-9375;
DATE	1988
ABSTRACT	This book provides an overview of issues concerning children and adolescents with spina bifida, including: health issues, medical problems, and developmental processes. The guide provides answers to common questions asked by families regarding both the psychosocial and physical aspects of spina bifida. The authors provide listings of: useful terms, relevant organizations, types of service providers that might be helpful, and other publications to which families might refer. (92 pages)

AUTHOR	Fraser BA; Hensinger RN;
TITLE	**Managing Physical Handicaps. A Practical Guide for Parents, Care Providers, and Educators.**
SOURCE	Paul H. Brookes: Baltimore;
DATE	1983
ABSTRACT	Based on their experience in a specific school district and medical center, the authors have developed a clearly written, well–illustrated handbook for those who provide daily care to children with physical disabilities. The authors describe in detail normal neuromuscular function and its restriction by spinal deformities, limb deformities, and postural abnormalities. Special communication techniques, handling of persons with severe disabilities, wheelchairs and other transportation, and current advances in the field of rehabilitation are discussed. (246 pages)

AUTHOR	Goldfarb LA; Brotherson MJ; Summers JA; et al;
TITLE	**Meeting the Challenge of Disability or Chronic Illness–A Family Guide.**
SOURCE	Paul H. Brookes: Baltimore;
DATE	1986
ABSTRACT	Book focuses on the process of problem solving for parents to give them the skills to meet the challenges posed by having a child with a chronic illness or disability. Unique and valuable tool for all families; also an important resource for professionals. (250 pages)

AUTHOR	Gordan J;
TITLE	**Give Me One Wish.**
SOURCE	W. Norton: New York:
DATE	1988
ABSTRACT	A mother's account of the life of her daughter who had cystic fibrosis and died at age 22. It focuses on the daughter's struggle in adolescence to keep up with her peers in the face of her advancing disease.

AUTHOR	Kaufman SZ;
TITLE	**Retarded Isn't Stupid, Mom.**
SOURCE	Paul H. Brookes: Baltimore, MD;
DATE	1988
ABSTRACT	Story of growing up with mental retardation. Shows how parents, families and young people with disabilities cope with the challenges and frustrations of everyday life. In an objective yet intimate manner, critical issues (employment, independent living, sexuality, marriage, health care, transportation) are presented. (246 pages)

AUTHOR	Lindemann JE; Lindemann SJ;
TITLE	**Growing up Proud: A Parent's Guide to the Psychological Care of Children with Disabilities.**
SOURCE	Warner Books: New York;
DATE	1988
ABSTRACT	This book discusses issues regarding children and adolescents with disabilities such as: psychosocial problems, developmental processes, family issues, sexuality, education, employment, community living, case management, advocacy, and interagency collaboration. (208 pages)

EDITOR	Mulick JA; Pueschel SM;
TITLE	**Parent–Professional Partnerships in Developmental Disabilities Services.**
SOURCE	Academic Guild: Cambridge, MA;
DATE	1986
ABSTRACT	Collaborative approach to providing service to children with mental and physical disabilities. Includes chapters on resources, shared decision making, families, and transition to adulthood. (242 pages)

AUTHOR	Perske R;
TITLE	**Circles of Friends.**
SOURCE	Abingdon Press: 201 Eighth Avenue South, P.O. Box 801, Nashville, TN 37202;
DATE	1988
ABSTRACT	This collection of "true stories" describes individual experiences of friendship between people with a wide range of disabilities and people without identifiable impairments. Discussions of the importance of such friendships to all concerned and the society at large are included. Sensitivity is employed in avoiding labeling. All ages are represented. (94 pages)

AUTHOR	Powell TH; Ogle PA;
TITLE	**Brothers and Sisters – A Special Part of Exceptional Families.**
SOURCE	Paul H. Brookes: Baltimore;
DATE	1985
ABSTRACT	This is a much needed book devoted to the impact of having a sibling with disabilities or chronic illness based on extensive review of the existing literature and the published experiences of such siblings. The author explores the special concerns of siblings, the bond between siblings with and without disabilities, strategies to help siblings and their parents, and the outcome for such siblings as adults. There is an extensive annotated guide to resource organizations and suggested readings. (248 pages)

AUTHOR	Semel RL;
TITLE	**The Third Strike. A Father's Story of His Son's Struggle with Cancer.**
SOURCE	Metamorphous Press: Portland, OR;
DATE	1985
ABSTRACT	This emotional book documents 12 years in a family's life from the initial diagnosis of rhabdomyosarcoma in their only son at age 8 to his death at age 20, following two recurrences and prolonged involvement with surgery, chemotherapy and radiation therapy. (252 pages)

AUTHOR	Shelton TL; Jeppson ES; Johnson BH;
TITLE	**Family–Centered Care for Children with Special Health Care Needs.**
SOURCE	Association for the Care of Children's Health, 3615 Wisconsin Avenue, N.W., Washington, D.C. 20016; 202/244-1801;
DATE	1987
ABSTRACT	Manual lays out eight key elements of family-centered care, research, check lists for states, communities, training programs, hospitals and research projects, and other resources. (Purchase price: $5.00 plus $2.50 shipping and handling; 74 pages)

AUTHOR	Simons R;
TITLE	**After the Tears–Parents Talk about Raising a Child with a Disability.**
SOURCE	Harcourt, Brace, Jovanovich, Inc.: San Diego, CA;
DATE	1985
ABSTRACT	Parents of children with disabilities describe how they first confronted their experiences of having a child and then recovered to emerge stronger, healthier, and able.

EDITOR	Summers JA;
TITLE	**The Right to Grow Up: An Introduction to Adults with Developmental Disabilities.**
SOURCE	Paul H. Brookes: Baltimore;
DATE	1986
ABSTRACT	Provides a sensitive appraisal of the changing emotional and physical needs of maturing young adults and offers means to evaluate quality of life, level of personal benefit and degree of freedom offered by any service program. (352 pages)

AUTHOR	Thompson C;
TITLE	**Raising a Handicapped Child: A Helpful Guide for Parents of the Physically Disabled.**
SOURCE	William Morrow and Co.: NY;
DATE	1986
ABSTRACT	This book provides practical suggestions for parents of children and youth with disabilities on a wide variety of issues. Appendixes include names of agencies concerning children with disabilities and a glossary of medical terms. (276 pages)

AUTHOR	Turnbull HR; Turnbull AP;
TITLE	**Parents Speak Out, Then and Now (2nd edition).**
SOURCE	Charles E. Merrill Publishing Co.: Columbus, OH;
DATE	1985
ABSTRACT	Collection of stories that describe the successes and failures of those who sought help for persons with disabilities and those who tried to provide it. Most of the contributors are parents. These stories dispell the notion, common among professionals and lay persons, that a child with a disability is invariably a burden and a cause of family distress. (287 pages)

AUTHOR	Turnbull HR; Turnbull AP; Bronicki GJ; et al;
TITLE	**Disability and the Family: A Guide to Decisions for Adulthood.**
SOURCE	Paul H Brookes: Baltimore;
DATE	1989
ABSTRACT	Practical information and steps for planning for the future of adolescents with disabilities. Includes legal, social–interpersonal, vocational and residential options. Methods for self–assessment, self–advocacy, and lists of resources to assist in planning are included. (432 pages)

TITLE	**National Directory of Organizations Serving Parents of Children and Youth with Emotional and Behavioral Disorders (2nd Edition).**
SOURCE	Research and Training Center, Regional Research Institute for Human Services: Portland State University, P.O. Box 751, Portland, OR 97207-0751; 503/725-4040;
DATE	1989
ABSTRACT	These United States organizations included provide one or more of the following services: education and information, parent training, case and systems level advocacy, support groups, direct assistance such as respite care, transportation and child care. ($8.00 per copy. Available from the publisher.)

AUTHOR	McManus MA;
TITLE	**Understanding Your Health Insurance Options: A Guide for Families Who Have Children With Special Health Care Needs.**
SOURCE	Association for the Care of Children's Health, 3615 Wisconson Avenue, N.W., Washington, D.C. 20016; 202/244-1801;
DATE	1988
ABSTRACT	An insurance guide which details public and private insurance options, including: Medicaid, Title V, traditional plans, HMO's, and preferred provider organizations. This "how-to" pamphlet provides answers to commonly asked questions, worksheets for comparing options, and suggestions on how to choose appropriate insurance coverage. A glossary of terms is also provided. (Available for $2.75 plus $1.00 postage and handling; 30 pages.)

TITLE	**Is an HMO Right for You? 2) Consumer Fact Sheet.**
SOURCE	Cystic Fibrosis Foundation, 6931 Arlington Road, Bethesda, MD 20814; 301/951-4422;
DATE	1987
ABSTRACT	Text supplies information allowing individuals to make informed decisions about health care financing. (No charge for these publications.)

TITLE	**Quality Health Care for People with Developmental Disabilities–A Guide for Parents and Other Caregivers.**
SOURCE	Center for Community Integration, 109 Pattee Hall, 150 Pillsbury Dr. S.E., University of Minnesota, Minneapolis, MN 55455, Attn: Beth Nelson; 612/624–6328;
DATE	1988
ABSTRACT	This health care guide is written for parents, advocates, helpers and friends who live and work with people with developmental disabilities. Starting with the premise that all people have a right to quality health care, this guide emphasizes that assisting people with developmental disabilities to obtain health care and maintain healthy life styles will enhance the quality of their lives in the community. This guide contains four major sections: 1) being a more effective consumer advocate in selecting and working with health care providers, 2) managing routine health care and developing healthy lifestyles, 3) managing common illnesses and more complex problems, and 4) finding resource materials and organizations of potential help in obtaining appropriate health care. In informal language, basic information is presented on daily routines such as nutrition and hygiene, as well as on more complex considerations such as determining which subtle changes signal a need to call a doctor. ($5.00 per copy payable to the University of Minnesota.)

TITLE	**Parent Primer. Secondary Programs for Students with Severe Disabilities.**
SOURCE	Parents Graduation Alliance, 135 Education, University of Oregon, Eugene, OR 97403; 503/346-5311;
DATE	1988
ABSTRACT	Describes features of educational excellence and offers information on how parents can help achieve it. (Available for $5.00.)

TITLE	**Educational Rights for Children with Arthritis: A Manual for Parents.**
SOURCE	Arthritis Foundation, 1314 Spring Street N.W., Atlanta, GA 30309; 404/872-7100;
DATE	1989
ABSTRACT	Learn how to ensure that children and youth with rheumatic diseases receive needed services in school using this manual. This 196-page self–teaching manual covers laws and terminology related to special education and explores communication and advocacy techniques that will help parents and professionals work together for the benefit of the child. Manual users will learn facts, gain skills, and find out about resources so children with arthritis can meet challenges and enjoy a happy and fulfilling school experience. (Available for $6.00.)

TITLE	**Strengthening Skills for Success: A Manual to Help Parents Support their Psychiatrically Disabled Youth's Community Employment.**
SOURCE	Thresholds Research Institute, 561 W. Diversey, Suite 204, Chicago, IL 60614; 312/348–5522;
ABSTRACT	This manual offers concrete suggestions for parents who want to support their child's vocational aspirations. Adolescent and work issues covered include those related to: job hunting, starting a new job, leaving a job, social skills, and stress management on the job. The manual focuses on helping parents feel better informed and more self–efficacious, regardless of whether or not their child is able to maintain community employment. The manual is intended for use by parents, educators, and mental health professionals. (Available for $5.50.)

III. MATERIALS FOR PARENT GROUPS

TITLE	**Parent/Professional Cooperation.**
SOURCE	Young Adult Institute, PID Tapes, 460 West 34th Street, New York, NY 10001; 212/563-7474;
DATE	1986
ABSTRACT	The relationship between parents and professionals is critical in providing care for individuals with developmental disabilities. Two professionals speak about methods of alleviating conflicts and developing a trusting relationship and team approach. Dr. Ann Turnbull and other parents of adolescents with developmental disabilities speak frankly of their many roles and frustrations, and of the need for communication and cooperation. This 30–minute videotape (1/2 inch and 3/4 inch) can be rented for $45 plus shipping or purchased for $75 plus shipping. The Young Adult Institute also has many other videotapes available on topics related to youth and the transition to adulthood.

TITLE **Working Together: The Parent/Professional Partnership.**
SOURCE Resource Services Coordinator, Research and Training Center, P.O. Box 751, Portland State University, Portland, OR 97207–0751; 503/725-4040;

ABSTRACT A trainers' guide for a one–day workshop for a combined parent/professional audience. Designed to identify perceptions parents and professionals have of each other and obstacles to cooperation, as well as discover the match between parent needs and professional roles, and practice effective listening techniques and team decision making. (Available for $8.50.)

TITLE **Parent to Parent Videotape.**
SOURCE Family Support Network of NC, CB 7340, Daniels Rd., Tr. 31, University of NC, Chapel Hill, NC 27599-7340; 919/966–2841;
DATE 1987

ABSTRACT This 12–minute videotape describes the Parent–to–Parent support model and its benefits to families of children with special needs. The tape was filmed at two parent–to–parent programs: Parents Reach Out in Burlington, NC and Parents Helping Parents in Fayetteville, NC and discusses training, matching, and meetings for parents. (Available for $7.50.)

TITLE **The Parent to Parent National Training Package.**
SOURCE Parent to Parent National Project, University Affiliated Program, University of Georgia, 850 College Station Road, Athens, GA 30610; 404/542–6629;
DATE 1984

ABSTRACT The 144 page manual and 10 video-taped training modules outline in detail a system of self–support for families who have a family member with a disability. Manual may be used alone, or in concert with videotapes, for step–by–step trainer–of–trainers instruction. Video module titles are: Introduction and Overview; Sensitization; Peer Help Skills—Didactic; Peer Help Skills—Role Play; Major Developmental Disabilities; Community Services; The Referral Process; Publicity; State Network; National Office. Note: Model is non-disability specific, i.e., generic in nature. (The purchase price of the entire training package is $160; the manual alone is $15. The package can be previewed for $21/10 working days which is applied to purchase price if the package is subsequently purchased.)

TITLE	**Home to Community Workshop for Parents of Secondary Age Students with Handicaps.**
SOURCE	PACER Center, 4826 Chicago Avenue, Minneapolis, MN 55417–1055; 612/827-2966.
ABSTRACT	This training package (Order #PHP-g3) includes the curriculum, 25 transparencies, and informational handouts for parents. (Available for $150.00.) PACER has many other materials available regarding youth with disabilities in the transition to adulthood.

TITLE	**It's Never Too Early, It's Never Too Late.**
SOURCE	Metro Council Data Center, Mears Park Centre, 230 E. Fifth St., St. Paul, MN 55101; 612/291-8140;
DATE	1988
ABSTRACT	An 11–minute video and book explain Personal Futures Planning (PFP), which is a process for creating a vision of the future for a person with a disability. The process consists of two meetings–one to develop a profile of the person's past history and one to plan the future. PFP focuses on a person's gifts and capacities and how those can be used to build a positive future. (The video is available for $12 from the source listed above; the book can be ordered at no cost from: Governor's Planning Council on Developmental Disabilities, Minnesota State Planning Agency, 300 Centennial Building, 658 Cedar Street, St. Paul, MN 55155; 612/296-4018.)

TITLE	**Lily: A Sequel.**
SOURCE	Davidson Films, Inc., 231 "E" Street, Davis, CA 95616; 916/753–9604;
DATE	1988
ABSTRACT	This 17–minute film/video follows up on the development of a young woman who was a pioneer in mainstreaming (as portrayed in the film/videotape LILY: A STORY ABOUT A GIRL LIKE ME). Lily, who has Down syndrome, is shown graduating from high school and entering a group home. Lily and her supervisor in a pizza restaurant discuss her employment situation. Lily and her mother discuss concerns about long term independence and sexuality. (VHS/16 mm rental: $40; VHS purchase: $190; 16 mm purchase: $250)

TITLE	**And Then Came John.**
SOURCE	Filmakers Library, 124 East 40th Street, New York, NY 10016; 212/808–4980;
DATE	1988
ABSTRACT	When John McGough was born with Down syndrome, his mother, Lee, was told to place him in an institution by everyone she trusted. She refused, and took John home. John's presence taught the family about loving and caring. But outside of the family, John faced a world of prejudice and rejection. After his graduation from high school, he became increasingly depressed. Then, John's life changed when his mother remarried and moved the family from urban Los Angeles to a warm and accepting small town. John blossomed, as an artist, a musician, and a beloved member of the community. In a stunning climax to the 36–minute videotape, and to John's life so far, he invited his "town family" to share in the celebration of his 26th birthday, and 200 people showed up. This film challenges stereotypes and shows how the attitudes of a society can encourage or destroy a person who has a disability. (Rental: $55.00; Purchase: $350.00)

IV. OTHER RESOURCES

NAME | **NATIONAL PARENT RESOURCE CENTER**

ABSTRACT | This parent–run resource system is designed to further the goals of family–centered, community–based comprehensive and coordinated systems of health care for children and adolescents with special needs and their families, providing technical assistance to parents and parent groups. Affiliated centers are:

Central Office
Federation for Children with Special Needs
95 Berkeley Street, Suite 104
Boston, MA 02116
617/482–2915

Midwest Regional Office
PACER Center
4826 Chicago Avenue
Minneapolis, MN 55417
612/827–2966

Northeast Regional Office
Parent Information Center
P.O. Box 1422
Concord, NH 03301
603/224–0402

South Regional Center
PEP, Georgia ARC
1851 Ram Runway, #104
College Park, GA 30337
404/761–3150

West Regional Center
Washington PAVE
12208 Pacific Hwy. SW
Tacoma, WA 98499
206/588–1741

NAME	**Exceptional Parent.**
ADDRESS	Psy–Ed Corp., 1170 Commonwealth Avenue, Boston, MA 02134;
PHONE	617/730-5800;
ABSTRACT	This journal specializes in parent issues for a wide range of disabilities of children and adolescents.

NAME	**Higher Education and Adult Training for People with Handicaps Resource Center (HEATH)**
ADDRESS	One Dupont Circle, NW, Suite 800, Washington, D.C. 20036–1193;
PHONE	800/544-3284 or 202/939-9320;
ABSTRACT	HEATH provides technical assistance and materials on postsecondary education options for students with disabilities

NAME	**National Information Center on Handicapped Children and Youth (NICHCY)**
ADDRESS	P.O. Box 1492, Washington, D.C. 20013;
PHONE	800/999-5599 or 703/893-6061;
ABSTRACT	NICHCY provides free publications on many issues related to the health and education of children and youth with disabilities.

NAME	**National Health Information Center**
ADDRESS	P.O. Box 1133, Washington, D.C. 20013–1133;
PHONE	800/336-4797 or 301/565-4167;
ABSTRACT	A project of the Office of Disease Prevention and Health Promotion of the U.S. Department of Health and Human Services, the Center operates an information and referral center to help consumers find health information by locating appropriate sources of information.

NAME	**National Rehabilitation Information Center (NARIC)**
ADDRESS	8455 Colesville Road, Suite 935, Silver Spring, MD 20910;
PHONE	800/34–NARIC;
ABSTRACT	NARIC produces and searches a database called REHABDATA, which is a collection of rehabilitation and disability–related bibliographic materials, and provides information and referral services to other organizations.

NAME	**National Maternal and Child Health Clearinghouse**
ADDRESS	38th and "R" Streets, N.W., Washington, D.C. 20057;
PHONE	202/625-8410;
ABSTRACT	This clearinghouse contains many publications on a variety of topics related to maternal and child health.

OTHER INFORMATION SOURCES ON YOUTH WITH DISABILITIES

HEATH Resource Center
(Higher Education and Adult Training for People with Handicaps)
One Dupont Circle, N.W.
Suite 800
Washington, D.C. 20036-1193
1-800-544-3284

NICHCY
(National Information Center for Handicapped Children and Youth)
PO Box 1492
Washington, D.C. 20013
1-800-999-5599

National Health Information Center
PO Box 1133
Washington, D.C. 20013-1133
1-800-336-4797

ERIC Clearinghouse on Handicapped and Gifted Children
Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
703/620-3660

National Rehabilitation Information Center
8455 Colesville Road
Suite 935
Silver Spring, MD 20910
1-800-346-2742

National Maternal and Child Health Clearinghouse
38 and "R" Streets, N.W.
Washington, D.C. 20057
202/625-8410

CYDLINE Reviews

Please copy and share the contents of this publication. We ask that you credit the National Center for Youth with Disabilities as the source of information.

National Center for Youth with Disabilities/Society for Adolescent Medicine

Staff

Robert Wm. Blum, M.D., M.P.H., Ph.D., Director

Nancy A. Okinow, M.S.W.
Executive Director

Gayle Geber, M.P.H.
Research Fellow

Karen J. Stutelberg
Administrative Officer

Elizabeth Latts, M.S.W.
Information Specialist

Harriet Kohen, M.A.
Program Associate

Wendy Wachter, B.A.
Director of Communications

Coordinating Council

Donald Orr, M.D., Chair
Director, Adolescent Health
Riley Children's Hospital
Indianapolis, Indiana

Dale C. Garell, M.D.
Medical Director
California Children's Services
Los Angeles, California

Lonnie Zeltzer, M.D., Head
Division of Child Development
& Biobehavioral Pediatrics
UCLA School of Medicine
Los Angeles, California

Arthur B. Elster, M.D.
Director, Department of
Adolescent Health
American Medical Association
Chicago, Illinois

Ex-Officio

Richard Brown, M.D.
President
Society for Adolescent Medicine
San Francisco General Hospital
San Francisco, California

Renee Jenkins, M.D.
Past President
Society for Adolescent Medicine
Howard University Hospital
Washington, D.C.

Edie Moore
Administrative Director
Society for Adolescent Medicine
Independence, Missouri

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National Center for Youth with Disabilities
University of Minnesota
Box 721 - UMHC
Harvard Street at East River Road
Minneapolis, MN 55455

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